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## Screening for Caregiver Role Strain Among Primary Care Providers

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**Screening for Caregiver Role Strain Among Primary Care Providers**

by

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A project

Submitted in Partial Fulfillment of the Requirements for the

Degree of Master of Science in Nursing, College of Nursing

and Speech-Language Pathology

Mississippi University for Women

**Graduate Committee Approval**

The Graduate Committee of Harlie Chandler, Katherine Jones, Jade Sullivan, Kayla Thomas, and Monica Williams hereby approves her research project as meeting partial fulfillment to the requirements for the Degree of Master of Science in Nursing

Date \_\_\_\_\_

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Director of Graduate Studies

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### **Dedication**

I would like to dedicate all of my arduous efforts in this program to my daughter, Remi Jane, to display to her that she can do anything in this world that she desires. Secondly, I want to express the utmost appreciation to my husband, Reed, for his overwhelming support. Lastly, I want to thank my wonderful mother-in-law, Lelia, and mother, Sonya, for unending babysitting hours and their continuous moral support. I would not be where I am today without them.

Harlie Chandler

I would like to dedicate my work to my husband, Austin, who has supported and encouraged me throughout this program. I could not have pursued my dream to be a nurse practitioner without him. I would also like to dedicate my work to my sons, Elliot and Isaac. They inspire me every single day and are the reason I chose to better myself and my career. I would like to thank my family for their never ending love and support.

Katherine Jones

This research is dedicated to my daughter, Loftan Marie. All of the hard work put into this research and program was to provide an example of hard work and perseverance, no matter the circumstances. I would also like to take this moment to thank my loving family. Surviving this past year wouldn't have been possible without all of your love and support. Lastly, I would like to thank my friends who have been listening ears and constant laughs when I needed them. God is good, all the time!

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I am dedicating this research to my wonderful family who has been my source of inspiration and strength. They have continually provided moral, spiritual, and emotional support, and I could not be more thankful. And most especially to our Almighty God. Thank you for the power of mind, guidance, and protection.

Kayla J. Thomas

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Monica Williams

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### **Abstract**

Following a diagnosis of terminal illness, more people are electing to remain home for care. The role of the caregiver falls to other family members or paid assistance from outside the home, which can become expensive. As the disease progresses and functional and mental deficits develop, the physical and emotional stressors of providing care can, over time, manifest in changes to the overall health of the caregiver. Even with paid assistance, the financial burden can worsen these stressors further. Early identification of caregiver role strain could allow providers to aid in linking available and appropriate resources that may be of benefit. The purpose of this study is to screen for provider knowledge and screening practices regarding caregiver role strain. The research integrates a descriptive, non-experimental, quantitative design using a convenience sampling of healthcare providers in the southern United States. Data was collected via Google Forms and distributed via social media platforms and provider databases. The researchers concluded that while healthcare providers are knowledgeable regarding caregiver role strain, they are not screening for role strain nor utilizing any screening tools.



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## Chapter 1: Dimensions of the Problem

Caregiver burden has been defined as the combination of physical, psychosocial, financial, emotional, and social stressors experienced by an individual as a direct result of providing care for another person (Brown et al., 2017). According to a study by Brown et al. (2018), the ratio of the aging population has been increasing worldwide. The percentage of individuals 60 years old and above is estimated to increase by more than 10% by 2050. This increase can be attributed to developments in medicine and technology that have led to better medical and diagnostic methods. Informal caregivers play an important role in managing the health, well-being, functional status, and quality of life of this aging population. More people are electing to remain at home as their health declines. The role of the caregiver falls to other family members or paid assistance from outside the home. In most cases, those providing care have little or no training in this area and do not receive additional support. As functional and mental deficits continue to decline, the stress of providing one on one care may have a negative effect on the caregiver. Caregiver burden can be associated with poor physical health, anxiety, and depression (Brown et al., 2017).

While some screening tools for caregiver burden are available, there is a general lack of evidence-based clinical standards for screening and identifying those in need of assistance (Brown et al., 2017). Another barrier to screening caregiver burden is that healthcare providers may only have limited time to address the needs of the care recipient. The caregiver may not recognize their stress as a legitimate concern and fail to discuss it with the providers. This ultimately leads to a higher risk for negative outcomes for the person receiving care such as premature admissions to nursing homes,

hospitalization, or death. Early identification of caregiver burden could allow providers the opportunity to share information on the available resources for support to those providing care. The aim of this study was to evaluate primary care providers' knowledge and screening practices regarding caregiver role strain.

### **Problem Statement**

The physical and mental demands related to caring for dependent patients has a direct impact on the health of those providing care. Caregiving could potentially be associated with numerous adverse impacts on the caregivers' health. According to a study by (Wang et al., 2019), caregivers have shown to have higher rates of depression, negative health behaviors and coping skills, and a decline in managing their stress. These studies have shown increased morbidity and mortality rates among the caregiver population, as well as financial strain. Caregiving also affects the physical and mental status of the caregivers. Caregiving is associated with higher levels of depression and lower levels of self-esteem. Caregivers typically seem to show a decline in physical health and are potentially at an increased risk for developing chronic illnesses. Due to the burden of caregiving, these caretakers could be impacting their health in a negative way, therefore proving the importance of screening these individuals (Wang et al., 2019).

### **Purpose of the Research Project**

The purpose of the study was to screen for provider knowledge and current screening practices regarding caregiver role strain.

## **Significance of the Research Project**

Role strain among familial or paid caregivers can increase the potential for negative effects leading to a decline in the physical and mental health of the caregiver. Adequate screening methods could help identify key predictors of role strain before demands of care overwhelm the caregiver. This study is significant to primary care providers, nursing, and clinical practice. From a nursing perspective, all personnel from licensed practical nurses to advanced practice registered nurses, take care of patients who are elderly or diagnosed with chronic diseases and disabilities. These patients are often taken care of at home by an informal caregiver. It is essential to discuss with patient caregivers the prevalence of caregiver role strain as well as interventions and resources that are available to them. It is important to educate the caregiver on the possible effects of caregiver role strain such as depression, anxiety, higher risk for chronic diseases, financial burden, and increased physical demand. Caregiver role strain can also cause decreased effectiveness on the caregiver's ability to perform their role effectively. Being unable to care for the care recipient adequately may have a negative impact on their health as well. Regarding primary care providers, it is important to discuss these aspects as a part of routine patient care to improve not only the health of the patient but also their caregivers.

## **Conceptual Framework**

The student researchers chose Dorothea Orem's theory of self-care to organize and guide the research project. Orem obtained her master's degree in nursing education at the Catholic University of America in Washington D.C. In 1959, Orem was employed as



an associate professor at the Catholic University of America. While she taught at the university, Orem continued working on her self-care deficit nursing theory. The goal of this theory was to better aid nurses' understanding of self-care needs by defining self-care and explaining the requirements needed to provide adequate self-care.

The self-care theory states that as humans, we must deliberately care for ourselves in such a way as to continue proper health and well-being (Karakashian & Smith, 2021). This must be learned and purposefully initiated along with commonly performed physical care needs, such as hygiene, eating, and sleeping. This applied to the project in that caregiver role strain can be considered a necessary assessment to maintain adequate self-care. High levels of caregiver burden are not uncommon in situations involving informal caregiving. Only after assessing patients in these types of roles can providers and caregivers begin to implement appropriate self-care interventions.

Dorothea Orem theorized that self-care is a necessary aspect of life so providers should also always strive to assess their patients and caregivers of their patients for high levels of caregiver burden (Alligood, 2018). Dorothea also theorized that self-care is a learned behavior (Alligood, 2018). Some caregivers might feel guilty about desiring time to themselves while not providing assistance to someone else. Screening practices are instrumental in improving recognition of caregiver role strain. Only after recognition of caregiver burden can providers then address the issue and propose treatment options.

## Research Questions

Three research questions were developed to guide data collection considering provider knowledge and current practices regarding caregiver role strain. The questions are as follows:

1. Are primary care providers knowledgeable regarding the effects of role strain on the caregiver?
2. Are primary care providers routinely screening for signs and symptoms of caregiver role strain?
3. Are primary care providers in MS using screening tools to identify caregiver role strain?

## Definition of Terms

For the purpose of this study, the researchers defined the following terms: primary care provider, knowledge, screening, caregiver, and role strain. An operational and theoretical definition is provided for each term.

### *Primary Care Provider*

**Theoretical:** The healthcare provider, including the nurse practitioner, physician's assistant, or physician, to whom a patient first goes to address a health problem (Venes & Tabor, 2017).

**Operational:** The nurse practitioner, physician assistant, or physician in the clinical setting.

### ***Knowledge***

**Theoretical:** A pattern of cognitive information related to a specific topic, or its acquisition, which can be strengthened (Venes & Tabor, 2017).

**Operationally:** Scoring a 70% or above on the knowledge portion of the survey.

### ***Screening***

**Theoretical:** The initial examination to determine the mental status of a person and the appropriate initial therapy (Venes & Tabor, 2017).

**Operationally:** The use of the survey to acquire knowledge of those interviewed.

### ***Caregiver***

**Theoretical:** One who provides care to a dependent or partially dependent patient (Venes & Tabor, 2017).

**Operationally:** Anyone who cares for another person who is sick, elderly, or disabled and answers the survey.

### ***Role Strain***

**Theoretical:** A great effort of an individual in relation to the group (Venes & Tabor, 2017).

**Operationally:** The amount of stress experienced by the individual in the position of caregiver.

## **Assumptions**

For the purpose of this study, the following assumptions were made:

1. The researchers assumed the primary care providers would answer the questions truthfully and honestly.
2. Participants were able to read and understand each question.
3. The researchers assumed the questionnaire would provide an insight on the importance of screening caregivers for possible role strain.

## **Limitations**

Limitations of the research study included electronic distribution of the survey and a time limit of four weeks to answer the survey. First, the electronic distribution of an online survey only reached providers that had access to social media and provider databases. Not all primary care providers participate in social media platforms nor do all providers have access to provider databases. Another limitation included a time limit of four weeks to reply to the student's survey. While four weeks could be an adequate amount of time for some participants to reply, there was a possibility that the specific four weeks chosen interfered with the providers' schedules. In addition to this, humans can be inherently forgetful. These limitations had the potential to cause a poor representation of caregiver burden assessment.

## **Summary**

Caregiver role strain is experienced when a caregiver feels overwhelmed and is unable to perform their role adequately. Role strain can be accompanied by feelings of stress and anxiety along with financial and physical strain. Caregivers often do not have the adequate training or resources to perform their role effectively. As the population ages and disability worsens, it is critical to understand the physical and mental health burden on caregivers. Gathering information on these topics enables healthcare providers to plan public health approaches to assist individuals as well as their communities and maintain the health of caregivers and care recipients. This study was significant to education, nursing, and further research. The results of this study proved the prevalence of caregiver role strain and the importance of recognition in the primary care setting.

## **Chapter 2: Literature Review**

Caregiver role strain negatively affects individuals from diverse populations. No race, sex, or ethnicity is immune to this kind of burden. Many informal caregivers may have never heard of caregiver burden or know that they are included in this population. Other caregivers may be aware of their role strain but are not knowledgeable of the resources available to them for this issue. Primary care providers are in the unique position of providing assistance to caregivers concerning role strain.

The purpose of this research project was to assess provider knowledge and their screening practices regarding caregiver role strain. Chapter II contains reviews of literature in which researchers assessed different aspects of caregiver burden. Reviewing other research projects involving caregiver role strain emphasized the need for further

research regarding caregiver role strain. The student researchers also reviewed studies that utilized Dorothea Orem's self-care theory as a conceptual framework.

### **Conceptual Framework**

For the purpose of this research study, the student nurse practitioners applied Dorothea Orem's Self-Care Theory as their conceptual framework. Orem's Self-Care Theory was pertinent to the current study because it views self-care as a normal human necessity that individuals must purposefully perform or have performed to maintain health, stability, and functioning in their life. According to Orem, self-care is vital for an individual's health, development, and well-being. This theory is important to the role of nurse practitioners because it stresses the importance of patients taking care of themselves to improve their overall health. This information was key when screening primary care providers about the knowledge of these practices. Therefore, primary care providers could be instrumental in improving recognition of caregiver role strain by utilizing Orem's theory (Alligood, 2018).

Orem defined her viewpoints within her theory with unique definitions. She defined self-care as activities performed by individuals to maintain life, health function, continued development, and general well-being for that particular individual. A person's own self-care was met by meeting functional and developmental requirements. Orem also defined these self-care requisites as a computed and expressed insight of actions needing to be performed that are considered necessary for human functioning and development. These universal self-care requisites included the maintenance of sufficient intake of air, food, water, and elimination processes. The maintenance of adequate activity, rest, and

social interaction were also included. Dorothea Orem also defined health deviation self-care requisites for individuals that are ill, injured, or with health conditions or disabilities. She believed that not only was physical and mental health affected, but also human functioning and development. She thought that the more complex the self-care deficit was, the more the health of that person deviated. This concept led her to define the therapeutic self-care demand, which summarizes the necessary care measures that should be met for individuals with health deviations. Within the Self-Care Theory, Orem stressed that self-care must be learned and performed purposefully and continuously to meet the requirements for an individual's overall well-being (Alligood, 2018). In an article written by Orem, she discussed her own theory and beliefs about nursing and the importance of self-care on an individual's health. She believed that the nursing role was vital in helping with a person's health, especially when that person had limitations in caring for his or her own self. According to Orem, nursing was applied when a person needed a nurse due to lack of his or her own self-care. Orem believed in the independence of a person's self-care actions (Orem & Taylor, 2011).

Following a study applying Orem's theory, the student nurse practitioners reviewed another article that puts Orem's Self-Care Theory into modern practice. Within this research article, the authors studied the impact of caregiving to those caring for patients with Alzheimer's Disease (Wang et al., 2019). In this article, the author noted how important self-care was and how this could be affected when caring for those with long-term illnesses. The author stressed how intensive caregiving can result in a physiological and psychological decline. Using Orem's theory, the author of this article set out to determine the impact of self-care management among caregivers of

Alzheimer's Disease patients. The results proved that caregiving did negatively impact these caregivers' self-care management. Wang et al. (2019), agreed with Orem's theory in which awareness, knowledge of self-care, and motivation, as well as knowledge of resources in self-care, were important in achieving self-care management (Wang et al., 2019).

Additionally, review of another research article by Shad et al. (2019) was done. In this study, Orem's Self-Care Theory was also used as the conceptual framework. This study aimed at determining if implementing a self-care program for hemodialysis patients would improve their health outcomes and life satisfaction. The author of this study took Orem's idea that humans have the ability to care for themselves, but whenever this is limited, the nurse provides direct care. Since hemodialysis patients are limited in their own self-care, Orem's theory of engaging in self-care activities was implemented. A few of the self-care activities the hemodialysis patients engaged in where controlling daily weight and blood pressure, adherence to dietary and fluid restrictions, activity, and sleep. The results of this research study proved Orem's theory to be effective. After implementing self-care activities with hemodialysis patients, their health and self-care maintenance did improve (Shad et al., 2019).

Orem's Self-Care Theory was used in guiding the student nurse practitioners in their own research study. The current study screened primary care providers on their knowledge of caregiver role strain. The researcher applied Orem's Self-Care Theory by acknowledging and agreeing on the importance that caregivers need self-care, and their self-care may be limited due to their obligations. Therefore, this proved a need for the current research study to determine if healthcare providers were screening these



caregivers for inadequate self-care in their practice. Orem's theory also applied in this current study utilizing the idea that when self-care is limited, such as when caring for others needs above themselves, primary care providers must step in and take action (Alligood, 2018).

### **Review of Related Literature**

Reviewing related literature further emphasized the significance of the current research study. The following literature reviews demonstrated the need for further research for caregiver role strain screening. The results of these literature reviews were also utilized as a comparison to the outcomes of the researcher's current study.

Lwi et al. (2017) studied the impact that caregiver stress has on the long-term health of patients. The purpose of this study was to show a correlation to poor caregiver mental health and patient mortality, especially among those who care for patients affected by a neurodegenerative disease. It was examined whether caregiver mental health predicted patient mortality above and beyond well-established patient risk factors (i.e., diagnosis, age, sex, dementia severity, patient mental health) and other caregiver characteristics that could influence mortality (e.g., caregiver physical health). The results revealed that caregiver mental health symptoms (measured with the SF-36) remained a significant predictor of patient mortality. The authors recorded that these findings indicate that worse caregiver mental health is a unique predictor of patient mortality even when accounting for patient variables and caregiver physical health (Lwi et al., 2017). The current researchers utilized this study to answer similar questions such as how

knowledgeable providers were about the correlation to caregiver mental health and the effect it has on the patient.

Overcash et al. (2019) used a cross-sectional study for the purpose of determining the predictors of strain among caregivers of older adults diagnosed with breast cancer. Overcash et al. (2019) hypothesized that certain characteristics of the caregiver and the care recipient could predict caregiver strain. The results showed that role strain was the most prevalent among the caregivers who were young and employed. The implication of this study was to show that screening for caregiver role strain should begin at initial visits and should be incorporated into the patient's care-plan. Knowing factors associated with influencing caregiver role strain could help healthcare professionals better assess role strain, which may improve the caretaker and the patient's health (Overcash et al., 2019).

Marino, Badana, and Haley (2020) conducted a study comparing stress levels, demands, and coping strategies of primary versus secondary caregivers of aging adults. The authors saw a lack of studies conducted on secondary caregivers' health status and inconsistencies between the few studies that had been conducted. Using the stress process theory, Marino et al. (2020) assessed the effects of the primary or secondary role position and the relationship to the care recipient on the health status of the caregiver. The researchers hypothesized that decreased health status would be more likely reported by children caring for their parents than that of friends and other family members. The researchers also wanted to compare the reported stress levels of primary and secondary caregivers after adjusting for the differences in levels of care required to provide to the care recipient. When using the stress process model, the levels of care provided were taken into account when comparing stress levels and health status of primary versus

secondary caregiving. There was also the possibility of inability to compare these two factors by using only demands of care.

Practically no differences were discovered between primary and secondary caregivers in the categories of age, sex, race, education, and relationship. Secondary caregivers were found to have higher income, as well as to be more likely to have a spouse. Children caregivers provided the longest amount of care while friends reported the least number of hours spent caregiving. There was not much difference in reports of emotional stress between primary and secondary caregivers. As for physical strain, primary and secondary caregivers reported about the same amount while providing care to a parent or other family member. For caregivers of friends, primary caregivers reported much more physical strain than secondary caregivers. Negative impacts on the health of the caregivers were reported much more in primary than secondary caregivers. This research article was pertinent to the student researchers' project in that it showed that further research is needed on this topic. Caregiver burden is widespread and is common among families worldwide. The research indicated that caregivers often included more than the care recipients' spouses. Screening practices should therefore include anyone assisting in caregiving, not just primary caregivers and/or spouses.

Wang et al. (2019) performed a study on self-care management among caregivers of dementia and Alzheimer's Disease patients. The purpose of the study was to investigate the impact that caregiving had on these caregivers. The authors of this study hypothesized that caregiving would greatly impact self-care among caregivers. Using Morse and Field's Method of Thematic Analysis to help guide the framework for this study, the researchers developed a questionnaire and interviewed willing participants who

fit their own research-specific guidelines. The participants of the study went through an interview process with an experienced nurse, and the answers to the survey questions were copied verbatim. Overall, the study consisted of 45 caregivers; the study found that what the researcher hypothesized was correct. Caregiving did greatly impact the caregivers' physical, mental, and social self-care management. The researchers of this study confirmed the need for more interest in this topic (Wang et al., 2019).

MacDougall et al. (2017) conducted a study on caregivers' self-efficacy for controlling upsetting behaviors, such as emotional eating, and how this impacted the health of these caregivers. The study aimed to examine ways that the strains of caregiving, brought on by the stress of these duties, impacted the self-efficacy of the caregivers' health and management of their own healthcare needs. Using the Stress Proliferation Model, the researchers used a survey to gather the information needed. The study included 158 participants who were mostly female caregivers. The results of the study correlated with the hypothesis that self-efficacy for controlling upsetting emotional eating, did impact caregivers. The results concluded that caregivers not only engaged in behaviors such as emotional eating, but also smoking and alcohol use to help manage their daily stress. The study also found that caregivers who were stressed had an increased BMI, and their overall health was being impacted in a negative way (MacDougall et al., 2017).

Keeton et al. (2020) completed their study in order to further assess informal caregiver well-being. Many caregivers are required to perform medical tasks for the care recipient, including anything from regular activities of daily living to making appropriate appointments and performing more in-depth medical/nursing tasks. The purpose of this

study was to assess how many caregivers regularly perform medical tasks and the relationship between self-reported well-being and medical task performance. The authors provide several examples of programs implemented to better prepare caregivers for this new role, but a majority of these studies had small sample sizes and/or were not able to show long-term results of the caregivers' health statuses.

Overall, the researchers found that performing medical tasks was conversely associated with the negative outcomes assessed (emotional stress, physical strain, and high burden of care). These findings reflect recent smaller studies on the same or related subject. Some other studies based on preparing caregivers for the performance of medical tasks show positive short-term effects. The researchers concluded that more research is needed to find which tasks are most difficult and which interventions provide the most positive and effective outcomes for informal caregivers. In relation to the students' research project, this study highlights the difficulties in assessing caregiver burden. So many different circumstances and conditions can worsen caregiver burden, and it is of monumental importance to understand how to assess this. While this study did not specifically screen healthcare providers for caregiver burden assessment, this study did ask participants if they were at all prepared by anyone prior to becoming a caregiver and performing medical tasks. Most people were not previously informed on this subject, so this further solidified the idea that more research is needed in this area in order to better prepare these caregivers, as well as to screen them for caregiver burden on a regular basis given its prevalence.

Brown et al. (2017) performed a research pilot study to see if the Caregiver Burden Alert Assessment Tool could be effectively utilized and accessible for different

health literacy levels in identifying caregiver burden among individuals providing care at home for patients with Alzheimer's Dementia. Caregiver burden can be defined as the combination of stressors that can be physical, psychological, financial, emotional, or social, experienced by persons that provide direct care to another individual. Brown et al. (2017) questioned whether an existing assessment tool, such as the Caregiver Burden Alert, can be adapted to provide a standardized method for screening for caregiver burdens that is easily understandable by different levels of health literacy. The authors wanted to find out if a screening tool would be helpful to caregivers in identifying better self-awareness of their situation. The study defined that overall, the participants felt that the CBA would be beneficial for caregivers of dementia patients and easy to use. It would help facilitate self-awareness and introduce someone to information they may not have prior access to. This would be useful in establishing evidence-based competencies for healthcare providers that could be incorporated into the health history for home care admissions and during primary care provider visits. Early identification and self-awareness can provide the opportunity for education and referrals that could lead to positive outcomes and prevent caregiver decline, premature nursing home admission, and hospitalizations.

The CBA tool is not recommended as a substitute for a formal assessment for symptoms of depression or anxiety. The primary goal for the use of the CBA is to increase awareness and help initiate discussions between caregivers and health providers about more formal assessments and the next step in a plan of care. This study is relevant to the current proposed study in that it identified assessment tools that are available to healthcare providers.

Krutter et al. (2020) performed a cross-sectional study that used a sequential explanatory mixed methods design comprising quantitative data from questionnaires and interviews with the purpose of exploring interprofessional cooperation in dementia care between physicians and home care nurses to assess their knowledge related to caregiver burden. This study compared attitudes, experiences, and opinions regarding family caregiver burden from physicians, nurses, and caregivers of patients with dementia. Prior studies showed that caring for a person with dementia requires significant physical, psychological, social, and financial demands. Krutter et al. (2020) attempted to identify that the prospective attitudes and knowledge toward caring for patients with dementia with physicians, nurses in-home care settings, and the actual individuals providing one on one care, were similar and required more training and intervention. This study was conducted in a rural area of Salzburg from November 2016 to May 2017. Family caregivers, general practitioners, and nurses in the homecare setting were administered questionnaires with group specific items related to caregiver burden. These questionnaires sought to gain perspectives on the burden of family caregivers of people with dementia, quality of life among the family caregivers, and limits of providing care at home versus early nursing home placement. General practitioners and nurses were given an open-ended question asking if they had one or more special qualifications related to dementia and/or geriatric psychiatry. The Barthel Index and the Nurses' Observation Scale for Geriatric Patients was used to assess 10 activities of daily living and weighted to come up with a total score of 100 representing independence levels related to ADLS. The sampling of practitioners was public register based. 172 general practitioners received a paper questionnaire in the mail. Nurses were recruited through local home care nursing services. Administrators of these organizations administered a paper questionnaire to their nurses. Family caregivers also received a questionnaire by mail

with a free return envelope. Family caregivers were screened for eligibility for semi-structured interviews from those that responded to a public invitation for participation in the study. A convenience sample of eight caregivers was subsequently interviewed. The guideline-based qualitative interviews consisted of four topics: challenges and experiences in providing care, availability and use of local healthcare services, a subjective opinion of general practitioners and home care nurses, and suggestions for improvement. The team received 55 questionnaires from general practitioners and excluded those with private practice or with dementia patients in nursing homes only. The final sample consisted of 50 GPs. A total of 140 homecare nurses completed the survey and 113 family caregivers completed the questionnaire. Education, lack of time, and remuneration were the main problems identified that affect teamwork. The results of the qualitative part of the study revealed eight broad sub-themes related to caregiver strain among family caregivers.

This study indicated a need for dementia-specific training and education on an interprofessional level that targets general practitioners and other healthcare professionals who are directly involved in the care of dementia in primary care. The collaboration between disciplines could close the gap between healthcare professionals and family caregivers, which would ensure high-quality primary care. Future research using the general population as a sampling frame and the application of a random sampling strategy would provide more reliable figures. Alternative modes of survey administration such as online surveys through databases or social media and telephone interviews might be a reasonable alternative to paper questionnaires. Studies of this nature can be beneficial in identifying gaps in knowledge and encourage better screening measures for healthcare professionals to utilize in identifying caregiver burdens.



Vara-Garcia and colleagues (2019) conducted a study to test the role of trait mindfulness on the relationship between caregiving stress and blood pressure in dementia caregivers. Being a dementia caregiver is a chronic stressful situation associated with the increased risk of developing cardiovascular disease (CVD). Vara-Garcia et al. (2019) formulated a hypothesis stating that trait mindfulness would moderate the relationship between the frequency of disruptive behaviors of the care recipient and BP. The results of this study suggests that high mindfulness may alter the effects of behavior problems on diastolic BP, which could be relevant for cardiovascular health risk in dementia caregivers (Vara-Garcia et al., 2019). The current researchers will utilize surveys to evaluate healthcare providers' knowledge and screening practices regarding caregiver role strain. This is necessary to do before it results in cardiovascular health complications. In light of the results of this study, training caregivers in mindful techniques may decrease the impact of caregivers' BP and ultimately diminish or minimize adverse cardiovascular outcomes.

Abreu et al. (2017) conducted a study to evaluate the extent of psychological distress of caregivers of people with dementia. Roughly 21% of Americans are caregivers. Many of these caregivers are assisting those with dementia. It is estimated that 47.47 people are living with dementia and this will steadily increase in the upcoming years. This rate will require new methods and new interventions of care. Abreu et al. (2017) formulated a hypothesis stating that caregivers of persons with dementia experience psychological distress in at least one dimension of the Brief Symptom Inventory (BSI). Following the analysis, the researchers determined that the hypothesis was statistically supported. Caregivers of persons with dementia experience psychological distress in at least one dimension of the Brief Symptom Inventory (BSI),

as 38.9% of caregivers showed psychological distress. Frequently, caregivers experience an emotional, financial, and physical strain due to the assistance they are providing. Often caregivers are overworked and overwhelmed which could have life-threatening effects on themselves as well as those they are providing care for.

Caregivers' emotional support and coping should be routinely reviewed as part of the assessment of patients with dementia. The issue described in this study is both relevant and necessary, as there is increased need for this to be addressed among healthcare providers. The researchers suggest that caregivers' knowledge and psychiatric health should be evaluated, as well as including the implementation of psychoeducational programs that focus on cognition, communication, and stress management.

## **Summary**

Caregiver role strain is becoming an increasing problem worldwide. It is probable that caregivers provide much of the long-term care for older adults in this country. Because of the burden of caregiving, many individuals may experience the ill-fated effects of caregiver burnout, such as depression, poor health, and decreased quality of life. If caregivers continue to suffer negative consequences from their caregiving role, increased morbidity and mortality may result for caregivers. Their well-being is an important public health concern because these caregivers serve a necessary role to patients. Caregiver self-assessment tools previously discussed in this chapter screen for role strain and provide insight on what to do next and where to find assistance. This study emphasizes the importance of screening and educating caregivers on resources regarding role strain.

### **Chapter III: Design and Methodology**

The purpose of the study was to screen for provider knowledge and current screening practices regarding caregiver role strain. The researchers sought to determine if primary care providers were knowledgeable regarding the effects of role strain on caregivers and how the provider screens for role strain. Role strain among caregivers may lead to a decline in the physical and mental health of the caregiver. Adequate screening methods could help identify key predictors of role strain before demands of care overwhelm the caregiver. In the following sections, the researchers discussed the design, setting, population, sample, methodology, and data analysis of the current study.

#### **Design of the Study**

The survey that was developed integrated a descriptive, non-experimental, quantitative design. This questionnaire was developed to assess healthcare providers' knowledge and screening practices regarding caregiver role strain. In this survey, there were 15 questions involving demographics, knowledge levels regarding caregiver role strain, and current screening practices assessing caregiver role strain. Data collection was obtained through convenience sampling and was distributed to primary care providers using provider databases and social media platforms pending IRB approval.

#### **Setting for the Research Project**

The setting of this research study involved primary care clinics in the southern United States. The survey that was developed for this research project utilized Google Forms and was distributed via provider databases and various social media platforms.

## **Population and Sample**

A quantitative study was used to obtain the data for the current research project. The 15-question survey was developed by the researchers and distributed to physicians, nurse practitioners, and physician assistants who practice in primary care clinics in the southern United States. The survey was distributed to provider databases and social media platforms. The sample consisted of no more than 500 participants.

## **Methods of Data Collection**

Prior to the initiation of data collection, this study was first submitted for approval to the Institutional Review Board (IRB) at Mississippi University for Women. Following approval from the IRB, the five team members submitted their own personally developed 15 question electronic survey that included demographics, knowledge of caregiver role strain, and screening practices of caregiver role strain among primary care providers. The survey was sent to primary care providers through professional databases as well as social media platforms. The survey was available online for a total of four weeks. The responses were collected anonymously and securely using Google Forms. The results were compiled and sent to a statistician for data analysis.

## **Methods of Data Analysis**

The research was conducted and recorded on a research data tool that was created by the five researchers. The tool addressed the research questions regarding primary care providers' knowledge and screening practice of caregiver role strain. Demographic

information, such as age, gender, race, and provider type was used in the tool. Data was compiled into an Excel spreadsheet and then sent to a statistician for formal analysis.

### **Other**

The survey did not ask for any identifying data such as the participants' names, date of birth, etc. The survey did not ask for any identifying information regarding patients. With the survey link, recipients selected whether to participate or not. The gathered data was sent to a statistician for analysis. No identifying information of the patient or provider was collected in the study. No identifying information of either the patient or provider was sent to the statistician. The results of the study have been used for research purposes only. The data aided in the assessment of provider knowledge and screening practices of caregiver role strain.

### **Summary**

This study focused on assessing the screening practices of caregiver role strain by primary care providers. The results that were obtained by this study helped the researchers determine if primary care providers are screening for caregiver role strain. The results also exemplified the knowledge of primary care providers regarding caregiver role strain.

## **CHAPTER IV: RESULTS**

The study was designed to evaluate knowledge and screening practices of caregiver role strain among primary care providers. While some measures for caregiver burden do exist, there is a general lack of evidence-based clinical standards for screening

and identifying those in need of assistance (Brown et al., 2017). The researchers assumed that caregiver role strain is not routinely screened for in clinical practice. The researchers sought specifically to answer the following questions: 1. Are primary care providers knowledgeable regarding the effects of role strain on the caregiver? 2. Are primary care providers routinely screening for signs and symptoms of caregiver role strain? and 3. Are primary care providers in MS using screening tools to identify caregiver role strain?

The methodology for this study was an electronic survey that included demographics, knowledge of caregiver role strain, and screening practices utilized among the primary care providers. The questionnaire was sent anonymously through a Google Form link by professional social media platforms and through private emails of known contacts. The questionnaire was developed by the researchers and designed to obtain data from primary care providers regarding knowledge of caregiver role strain, screening practices, and demographics. The survey consisted of 15 questions, and each question was analyzed separately. The rest of this chapter provides the demographic findings, statistical results, and a summary of the statistical results of data collected.

### **Profile of Study Participants**

A quantitative study was used to obtain data for the current research. The survey questionnaire was designed to evaluate primary care providers' knowledge and screening practices regarding caregiver role strain. The questionnaire was sent to licensed medical providers in the southeastern United States via Google Forms to personal emails obtained by researchers from known contacts and other social media platforms. Demographic data

obtained included degree type, years of experience, primary patient population, and work setting.

The participants accessed the survey link, which was shared through professional Facebook groups or emailed via the Google Doc link. A total of 79 respondents participated in this survey. Of the 79 respondents, a total of 60 respondents were eligible to complete the survey since they reported being at least 21 years old and providing care to patients who require long-term care by an alternate caregiver. The survey was available for one month. 88.33% of the participants were nurse practitioners, 3.33% were medical doctors, 1.67% were doctors of osteopathic medicine, and 6.67% answered “other”. Demographics, including, degree type, years of experience, primary patient population, and work setting, were collected. Of the 79 participants, 45% have been practicing for 0-5 years. 25% of the participants have been practicing for 11-20 years and 15% report practicing for longer than 20 years. 85% of participants reported that their majority patient population was adults while 11.67% reported they mostly saw geriatrics patients. Only 3.33% reported a majority of the population in pediatrics. Knowledge and personal practice questions were also asked of the participants.

### **Statistical Results**

As initially stated in Chapter I, the researchers developed the following research questions to be answered:

1. Are primary care providers knowledgeable regarding the effects of role strain on the caregiver?

2. Are primary care providers routinely screening for signs and symptoms of caregiver role strain?
3. Are primary care providers in MS using screening tools to identify caregiver role strain?

Subsequently, the researchers created a 15-question survey to assess practices of healthcare providers, with 10 questions involving knowledge of caregiver role strain. These surveys were distributed via social media platforms and provider databases and were answered on a volunteer basis.

***Question 1: Are primary care providers knowledgeable regarding the effects of role strain on the caregiver?***

In the survey, questions six, seven, eight, nine, and ten were assessing providers' knowledge on the definition of caregiver role strain and its effects on the caregiver. Question six asked participants if he or she was familiar with recognizing caregiver role strain in clinical practice. 80% of respondents answered "Yes, very familiar", 20% of respondents answered "No, not very familiar", and no respondents answered "Not familiar at all". Question seven asked, "How would you define caregiver role strain?". 90% of participants answered correctly, with the "All of the above" option. 8.3% answered "Both A & B" and one participant selected "Increased responsibility".

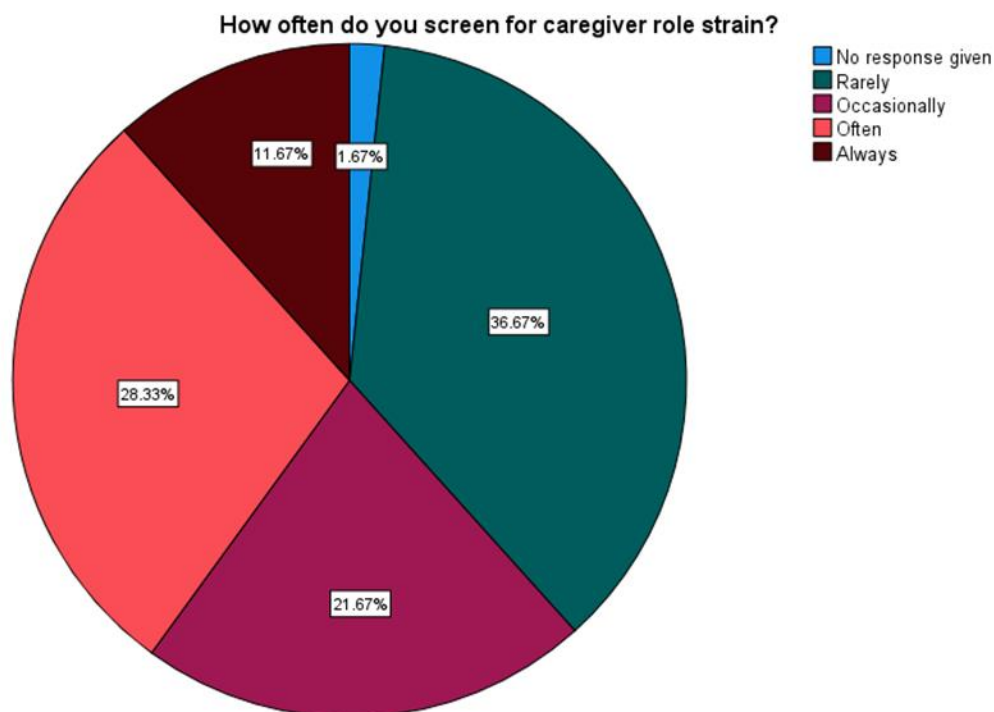
Number eight was a true or false type question, stating "Caregivers who attempt to balance caregiving alone with maintaining their work and family life may find it difficult to focus on the positive aspects of caregiving and have an increased sense of burden". 100% of participants selected the correct answer, which was "True". Question



nine asked, “Choose the correct definition for caregiver role strain”. 90% of survey participants selected the correct answer, “The amount of stress experienced by the individual in the position of caregiver”. 6.7% of participants selected “Stressful period in which someone wants to become a caregiver for another person”. No participants selected either of the two remaining choices. Two participants did not answer the question. Question 10 requested participants to choose “Which of the following are risk factors of caregiver role strain?” All participants chose “All of the above”, which was the correct answer.

***Question 2: Are primary care providers routinely screening for signs and symptoms of caregiver role strain?***

Questions 11, 12, 14, and 15 involved screening practices of providers for caregiver role strain. Question 11 asked, “How often do you screen for caregiver role strain?”. 36.7% of participants chose “Rarely”. 21.7% of participants chose “Occasionally”. 28.3% of providers said they screen often and 11.7% stated they always screen. One participant gave no response (see Figure 1).

**Figure 1*****Frequency of Screening Practices***

Question 12 asked “How often do you witness the effects of caregiver role strain?”. Most participants answered “Frequently”, with responses at 66.7%. 16.7% of participants answered “Very Frequently” and 16.7% chose “Seldom”. No participants chose “Never”.

Question 14 asked who the provider would screen for caregiver role strain. Responses were gathered at 6.7% for “Caregiver of your established patient”, 5% for “Established patient that has a caregiver role”, and 61.7% for both. 26.7% of participants said they do not routinely screen. Question 15 asked providers, “Which of the following may influence your ability to properly screen for caregiver role strain?”. 31.7% of participants chose “lack of time in clinical practice”, 3.3% of participants chose “topic

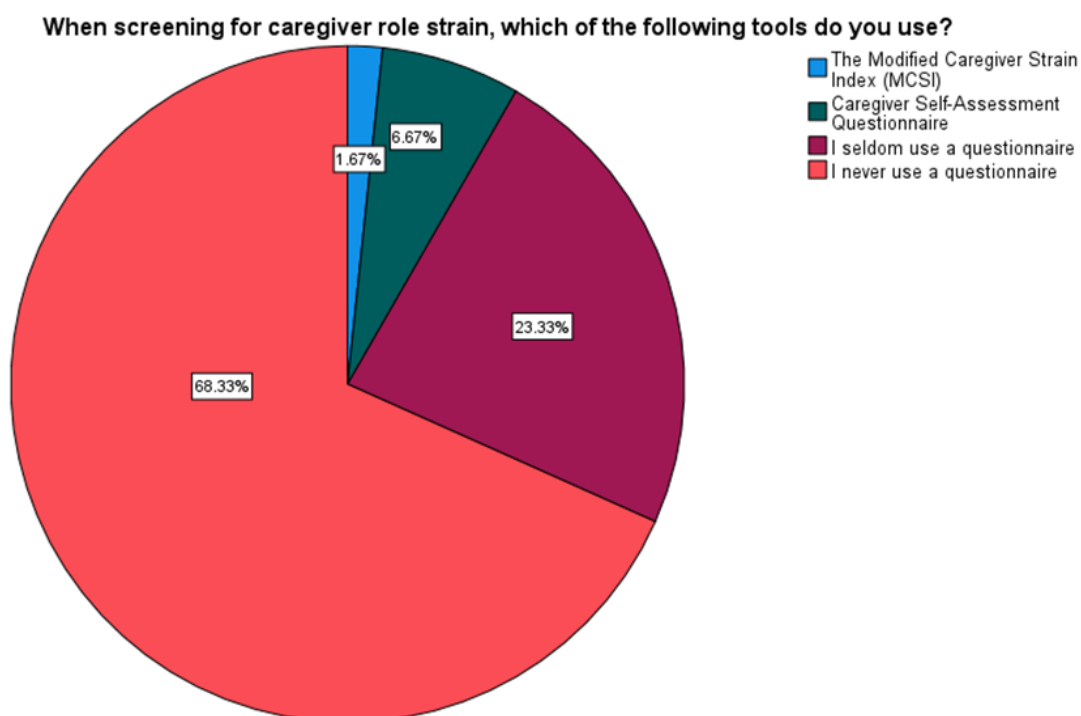
sensitivity”, and 8.3% of participants chose “lack of resources”. 56.7% of providers chose all of the reasons listed.

***Question 3: Are primary care providers in MS using screening tools to identify caregiver role strain?***

Question 13 of the survey asked providers which screening tool they use when screening for caregiver role strain. One response was given for The Modified Caregiver Strain Index (MCSI) (1.7%, N=1). Four providers chose the Caregiver Self-Assessment Questionnaire (6.7%, N=4). 23.3% of responses stated that they seldom use a screening tool, while 68.7% stated that they have never used a screening tool (see Figure 2).

**Figure 2**

***Assessment of Screening Tools Used***



**Summary of the Findings**

The study's goal was to evaluate if primary care providers were knowledgeable regarding the effects of caregiver role strain. The researchers also sought to find out if primary care providers routinely screened for caregiver role strain among their patients, and if so, how they were screening their patients. Questionnaires were removed from the results if the participant was not 21 years of age or older and was not currently providing care to patients who require long-term care by an alternate caregiver. This left a total sample of sixty questionnaires for analysis. Most of these questionnaires were completed by nurse practitioners with less than five years of experience. The majority of respondents reported working in primary care clinics with the majority patient population being adults. Participants were considered knowledgeable if they scored eighty percent or above on the knowledge questions. The mean score for the knowledge questions was ninety-two percent ( $SD=12.32$ ). The mean score of the sample was much higher than eighty percent,  $t(59) = 7.54, p<.001$ . Based on the study results, primary care providers in this sample were knowledgeable regarding caregiver role strain and the effect role strain has on caregivers. As predicted, the primary care providers in this sample are not routinely screening for signs and symptoms of caregiver role strain. In this sample, primary care providers are also not utilizing screening tools to identify caregiver role strain.

## **CHAPTER V: IMPLICATIONS**

As stated previously, caregiver burden can potentially cause physical and mental problems and ultimately affect a variety of populations. Many caregivers may not even realize the mounting burden this role has on his or her own health. While

trying to care for a family member or loved one, the caregiver could detrimentally be causing serious health outcomes for his or her own health. Some caregivers may realize the toll this role takes, but do not seek help or know about resources available for this type of issue. Providers must realize this dilemma and act on the problem at hand. According to a study by Lwi et al. (2017), caregiver stress greatly impacts the long-term health of the individual and can be a great predictor to patient mortality.

The purpose of this research study was to screen for provider knowledge regarding caregiver role strain and determine if providers were routinely screening for caregiver role strain. Using Orem's Theory on Self Care as the conceptual framework, the researchers adequately evaluated knowledge of providers among caregivers and determined that the knowledge was present, yet implementation of screening this vulnerable population was not. The findings indicated that, overall, providers were aware of the issue of caregiver role strain, but were not routinely implementing screening for caregiver role strain in their practice.

Using a detailed compilation of comprehensive literature review regarding caregiver role strain, along with the Self Care Theory as the framework to guide this study, the researchers developed a questionnaire to assess the knowledge of providers among a variety of healthcare settings. The researchers in this study developed three questions to guide their research, assuming the participants would answer truthfully and honestly to the best of their ability. This chapter will present a narrative of key findings of the study, providing a discussion of the results, implications, limitations, and further recommendations.

## Discussion of the Findings

The researchers did not meet their goal of 500 participants. A total of 79 respondents participated in the study, with only 60 of these participants being eligible to fully complete the survey. After critical analysis of the results, the researchers concluded that there was adequate knowledge of providers regarding caregiver role strain. Of the 60 eligible respondents, the majority of them were nurse practitioners working in primary care clinics, with 5 years or less of experience. The majority of these providers cared for the adult population, where caregiver activity is mostly prevalent. Of these results, the participants' answers correlated with the researchers' hypothesis of which they were familiar with recognizing caregiver role strain within their practice.

When asked the question of how often they screened for caregiver role strain, the respondents' answers directly correlated with previous assumptions. The majority of respondents answered that they rarely screen for caregiver role strain. Regarding the question of how frequently the providers witness the effects of caregiver role strain, the majority of the respondents answered "frequently". These results correlate with the previous literature reviews by Krutter et al. (2020) that found that providers required more training and intervention about the burden of caregiving.

Another finding within the study was that the majority of the providers admitted they have never used a screening tool. The majority of the respondents also acknowledged that the lack of time, topic sensitivity, and lack of resources influenced their own ability to properly screen for caregiver role strain during practice. A study by Keeton, Task, Whitney, and Bell (2020) correlated with this aspect that medically

necessary tasks, such as screenings, were not performed due to lack of knowledge and comfort.

In conclusion, the researchers of the study found that their own hypothesis was correct. The researchers concluded that the providers did indeed have the knowledge of caregiver role strain and that they did witness caregiver role strain very frequently within their practice. However, as hypothesized previously, most of the participants in this study did not have a screening tool and were not routinely screening for caregiver role strain.

### **Limitations**

Limitations of the study included a time frame of four weeks for survey availability, an online survey platform, a small sample size, and only surveying healthcare providers. First, the survey was only available to answer for four weeks. The researchers may have been able to reach more respondents with a longer time frame. Secondly, the survey was only available on an online platform. This was a limitation as not every provider may not have the ability to participate online. A paper copy of the survey to distribute would have reached more respondents or would have been easier for some providers to answer. Limitations such as a small timeframe and online platform assisted in creating a small sample size, which is the third limitation of the study. A total of 79 responses were collected, with only 60 of those completing the entire survey. The small sample size does not adequately represent the target population of healthcare providers.

## **Implications**

This study was intended to screen for provider knowledge and current screening practices regarding caregiver role strain. It was determined that providers are knowledgeable in recognizing role strain but do not routinely screen for this in practice. The position of the provider gives the opportunity to provide strategies to identify and manage the adverse effects of role strain. The implications of this study support the need for better education on this topic for providers that include screening tools, resource availability, and interdisciplinary support from other members of the healthcare team. The findings from this study support the need for future research that could aid in the development of better screening tools and measures to overcome time constraints that can limit screening by providers. The research team utilized Orem's theory to guide this project. The theory fully supported the need for management of self-care to promote better health outcomes in caregivers. Patient and caregiver education is a vital component of the provider's role in patient care. More education on early identification and screening would aid providers in meeting this need.

## **Summary of Findings**

The 15-question survey was answered completely by 60 individuals. 80% of the study participants responded that they are familiar with recognizing caregiver role strain in clinical practice. Overall, participants in this survey were considered knowledgeable regarding caregiver role strain and its effects upon the caregiver with a mean score of 92% on the knowledge questions. 58.4% of respondents reported that they only occasionally screen or rarely screen for caregiver role strain. Only 40% responded that



they often or always screen for caregiver role strain, even though the majority reported that they frequently witness caregiver role strain within their practice. No participants reported that they have never witnessed caregiver role strain while 83.34% reported they either frequently or very frequently witnessed caregiver role strain. 68.33% reported they have never utilized a screening tool for caregiver role strain. 56.67% of participants reported lack of time in practice, topic sensitivity, and lack of resources as the influences that affect their ability to properly screen for caregiver role strain. Even though primary care providers are knowledgeable regarding caregiver role strain, the majority do not routinely screen for it. This is likely due to the lack of resources, time constraints, and topic sensitivity within practices.

### **Recommendations**

Recommendations for this study primarily include correction of the limitations. For future research, increasing the sample size and expanding the geographical area would provide a better representation of a vast population. The study primarily included healthcare providers in Mississippi. A larger sample size would provide better insight regarding providers' knowledge and screening practices regarding caregiver role strain. Expanding the platform for participants to complete the survey, such as hard copies, could also acquire more participants. Another recommendation would be to include nurses in the research study, as they also come into contact with caregiver role strain. The last recommendation for further research would be to allow more time to complete the study. The limited time used in this study may have limited the sample size. By providing additional research time to complete the study, a greater variety of providers would pose more accurate results.

## Conclusions

The goal of the research study was to determine if healthcare providers are knowledgeable of caregiver role strain and proper screening methods to identify it. Based on the survey results, primary care providers are knowledgeable regarding the effects of role strain on the caregiver, but are not routinely screening for signs and symptoms of caregiver role strain. There are limitations in this study that can be corrected or improved for further research studies. The findings that were revealed in this study indicate an immediate need for healthcare providers to be diligent in screening for the effects of caregiver role strain. Primary care providers know first-hand the effects that caregiver role strain can have on a caregiver as well as the patient. Future research should be conducted to determine why providers are not routinely screening for caregiver role strain. It is imperative that healthcare providers are not only knowledgeable of, but are also screening for signs and symptoms of caregiver role strain.

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## Appendix A

### Letter of Approval from Institutional Review Board

To: Katherine Jones and Dr. Lindsay Kemp

From: Irene Pintado, IRB Chair *I.P*

Date: 05/10/2022

Project: Evaluating primary care provider knowledge and screening practices regarding caregiver role strain.

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The Mississippi University for Women IRB committee has determined that your project, Evaluating primary care provider knowledge and screening practices regarding caregiver role strain, is exempt under 45 CFR 46.101 (b)(4). This project is a quality assurance project.

If any changes are made to the study, the Committee must be notified. If the project is still running twelve months after the date of this memo, please be advised that we will need an update for our files.

Good luck with your work!

## Appendix B

### Caregiver Role Strain Survey

#### Demographics

What type of healthcare provider are you?

- Nurse Practitioner
- Medical Doctor
- Physician's Assistant
- Doctor of Osteopathic Medicine
- Other

How long have you been practicing as a licensed healthcare provider?

- 0-5 years
- 6-10 years
- 11-20 years
- > 20 years

What is your majority patient population?

- Adult
- Adolescent
- Pediatric
- Geriatric
- Other

In what type of setting do you practice?

- Primary care
- Urgent care
- Hospital
- Internal medicine
- Geriatrics
- Other

Are you 21 years of age or older and provide care to patients who require long-term care by an alternate caregiver?

- Yes
- No

### **Knowledge**

Are you familiar with recognizing caregiver role strain in clinical practice?

- Yes, very familiar
- No, not really familiar
- Not familiar at all

How would you define caregiver role strain?

- Financial burden
- Increased responsibility
- Role change in life



- All of the above
- Both A & B

Caregivers who attempt to balance caregiving alone with maintaining their work and family life may find it difficult to focus on the positive aspects of caregiving and have an increased sense of burden.

- True
- False

Choose the correct definition for caregiver role strain:

- Stressful period in which someone wants to become a caregiver for another person
- The amount of stress experienced by the individual in the position of caregiver
- Personal bias towards caregivers' decisions
- A disdain for children

Which of the following are risk factors of caregiver role strain?

- Impaired mental health
- Substance abuse
- Higher risk of chronic diseases
- All of the above

### **Current Practice**

How often do you screen for caregiver role strain?

- Rarely
- Occasionally
- Often
- Always

How often do you witness the effects of caregiver role strain?

- Very frequently
- Frequently
- Seldom
- Never

When screening for caregiver role strain, which of the following tools do you use?

- The Modified Caregiver Strain Index (MCSI)
- Caregiver Self-Assessment Questionnaire
- I seldom use a screening tool
- I have never used a screening tool

Who would you screen for caregiver role strain?

- Caregiver of your established patient
- Established patient that has a caregiver role
- Both A & B
- I do not routinely screen

Which of the following may influence your ability to properly screen for caregiver role strain?

- Lack of time in clinical practice
- Topic sensitivity
- Lack of resources
- All of the above